

Commentary

A mother's fear from Uganda: A story told and lessons to be learned

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The story of a mother, Mirembe (not her real name)

This is a real-life story of one mother's experience as she sought health care services to save the life of her child. The story provides a spectrum of lessons to health care providers as it brings out the expectations of both patients and caregivers.

At age 23, Mirembe had had four pregnancies. However, she had only one living child who was 3 years old. There is a strong belief in witchcraft in Mirembe's community, related to school completion. Mirembe stopped school in grade three as she believed that she would have been harmed by neighbours if she had completed grade seven. She lived with her husband who earned his income through tea growing. When I visited Mirembe at home, she shared her story about the recent death of her child.

HER STORY

Omwana wangye akazarwa aine amagara marungi (My child had good health at birth); she looked like any other normal child. She suddenly got sick; I tried to take her to clinic but there was no improvement. She got worse when she started vomiting everything and developed diarrhoea at the same time. Finally, my husband and I decided to take her to a government health centre where we met doctors from a higher-level hospital and they offered to refer and take us with them to hospital. This raised some hope that our child would get better. I went with my husband. I knew doctors were going to use a scan and tell me what my child was suffering from. This was important because I had a feeling that my child had been bewitched. My husband had a quarrel with someone who claimed that we had stolen his UGX 50,000 (20 Canadian dollars). This happened the past Saturday and the following Wednesday, the health of my child became worse, so I thought this man could be the cause.

When we reached the hospital, my child was admitted, started feeding in a tube and was put on oxygen. Before the

baby got fine, a nurse came and removed the oxygen, yet the baby's condition was not improving. The doctor came later and asked who removed the oxygen. I did not know the name of the nurse because I could not read her tag. The doctor put back the oxygen. I started asking myself if my baby was in safe hands. Another nurse took a blood sample but did not bring the results. The doctor asked me where the results were but I could not remember the name of the nurse. Remember, this was my first time to go outside my village. Everything was new to me. It was as if I was abroad. On top of a lot of learning, I was always asked which nurse did this and that, as if these are people I stay with and therefore know their names. Young nurses speak in English which was so hard for me. At least senior nurses spoke in my language and are more close to us, but they are not many.

In hospital, there are no supplies. One is asked to buy everything otherwise, you keep waiting. When my husband went home to look for money, I stayed alone and was asked to buy some things which I could not afford. My child missed treatment three times, which made me lose hope that she would get fine. I accepted to come to hospital because I knew they were going to tell me the problem of my child but no one told me. I wanted someone to do a scan of the stomach of my child and tell me what the problem was.

I decided to go back home before my child died in the hospital. I fear dead bodies, and here I was alone in the hospital. At least at home my mother-in-law could help when the baby dies. I got up very early and hired a motorcycle and driver and went back home. I could not go by taxi; taxis can be slow and I feared the baby could die on the way in case of delays. At home everybody saw that the baby was too ill to get well and therefore advised me not to go to any other health facility. In the evening of the same day I arrived home, my child passed on.

This problem is common in children in my community. Even my neighbour's child has the same condition. Most children here are dying of the 'disease of wounds'. You can see the

wounds in the mouth and they are also in the stomach. A lot of children have died of this problem here. We need help!

Not everyone can go to hospital. Our clinics are good; they treat our children and accept payments in bits, but here we produce a lot of children and treatment is very expensive. We fear using family planning due to its side effects. The experience can be bad and when you do not produce children, your husband will marry other wives.

CONCLUSION

There are many lessons here for all of us who provide care, regardless of the setting. This mother and this village need

help and understanding. We in the formal health system all too often do not explain what is going on in terms that mothers such as this can understand. This is not just a low-income country problem. Variations can be seen around the globe and across health systems. Trust is only built through good communication—the best care can fail to be accepted and followed if trust is not built.

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